What is the ADDM Network?

The Autism and Developmental Disabilities Monitoring (ADDM) Network is the only collaborative network to track the number and characteristics of children with ASD in multiple communities in the United States. Since the launch of the ADDM Network in 2000, CDC has funded 14 sites in areas of Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin. The ADDM Network sites are selected through a competitive award process and are not intended to form a sample that represents the nation as a whole. The ADDM Network sites all collect and analyze information using the same tracking method, which is modeled after CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP). MADDSP represents the Georgia ADDM Network site.

The ADDM Network's goals are to
- Obtain as complete a count as possible of the number of children with ASD in each ADDM Network area and identify changes in that count over time.

- Provide information on the characteristics, including sex, race/ethnicity, co-occurring intellectual ability, and age of evaluation and diagnosis, of children with ASD.

- Determine whether ASD is more common in some groups of children (for example, among boys versus girls) than among others, and if those differences are changing over time.

- Understand the impact of ASD and related conditions upon children, families, and communities in the United States.

What is prevalence?

The ADDM Network tracks the prevalence of ASD among children. Prevalence is a scientific term that describes the number of people with a disease or condition among a defined group at a specific period in time. For example, CDC estimated the prevalence of ASD among 8-year-olds in 2012 in metropolitan Atlanta, Georgia, by counting all of the 8-year-olds in metropolitan Atlanta who were identified with ASD, and then dividing that number by the total number of 8-year-olds living in metropolitan Atlanta during 2012. The resulting number is usually expressed as a percentage or proportion of the defined group.

Number of 8-year-olds with ASD

Total number of 8-year-olds

= PREVALENCE

What are the different ways of estimating the number of children with ASD?

There are several different ways to estimate the number of children with ASD, and each method has its advantages and disadvantages.

Method	What Is It?	Advantages and Disadvantages
Population-based screening and evaluation	Screening and evaluating a sample of all children in a population.	Can provide high accuracy, but can be costly and time-consuming, and might produce skewed results based on who agrees to participate.
National surveys	Collecting information via standardized instruments such as telephone interviews or self-completed questionnaires.	Is representative of national characteristics, but might reflect bias based on who participates and how ASD is defined and reported.
Registries	Collecting information on children and families who voluntarily include themselves on a list of people affected by ASD.	Relatively low cost, but time-consuming and includes only individuals with a clear diagnosis and families who know about the registry and are willing to be on the list.
Administrative data	Looking at codes for services in records from Medicaid and agencies such as the U.S. Department of Education.	Relatively low cost, but can underestimate prevalence because not all children with ASD are receiving services for ASD or have been diagnosed with ASD.
Systematic record review (ADDM Network's Method)	Reviewing health and special education records to identify children with ASD behaviors.	Relatively cost-effective and uses multiple data sources to identify children who might not have a clear ASD diagnosis already, but relies on the quality and quantity of information in records and, because data collection is retrospective, it is not always timely.

What is the ADDM Network's method?

The ADDM Network estimates the number of children with ASD using a record review method. Trained abstractors review records at sources in the community that educate, diagnose, treat, and/or provide services to children with developmental disabilities. It is important to note that this review does not only rely on a child having an ASD diagnosis, but also includes review of records for children with documented behaviors that are consistent with ASD. Abstracted information from all sources for a child is then reviewed by trained clinicians who determine if the child meets the definition of ASD using the *DSM-IV-TR* criteria.

Community partnerships are the key.

STEP 1
Collect data where children are served in the community.

STEP 2
Review compiled data and determine if child has ASD.

ASD?

STEP 3
Analyze data.

STEP 4
Report data back to the community.

What are the advantages of the ADDM Network method?

There are several major advantages to using the ADDM Network method for tracking the number and characteristics of children with ASD. For example, the ADDM Network
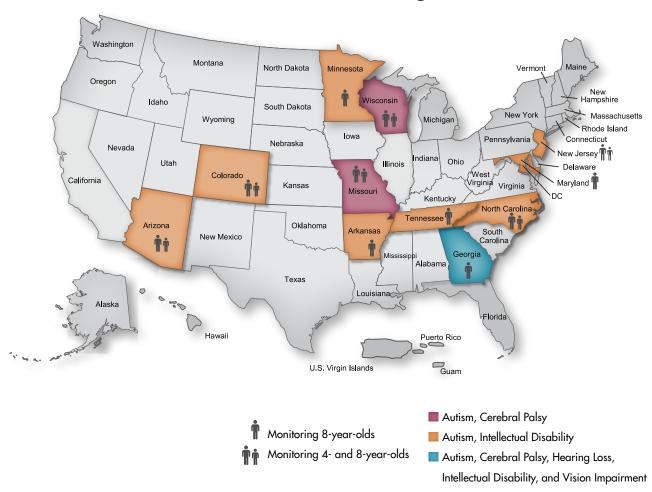
- Is the largest, ongoing ASD tracking system in the United States.

- Uses a method that is population-based, which means we try to identify all the children with ASD from the entire population of children in a defined geographic area (or multiple geographic areas).

- Can track changes over time within different communities and within different groups (such as racial/ethnic groups)

- Collects information from multiple sources in the community where children are served, including schools and local clinics.

- Uses expert reviewers to make a decision about whether a child has ASD based on review of symptoms documented in multiple records This means children with ASD are included in the total count even if they did not have an ASD diagnosis in their records.

DSM-5 and the ADDM Network

In May 2013, the American Psychiatric Association released a new edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), which is what doctors and other service providers use to diagnose mental disorders and conditions among children and adults. This new edition, also known as DSM-5, includes new criteria for diagnosing children and adults with ASD. **It important to note that the findings in this Community Report are based on information collected in 2012 before the DSM-5 was being used by doctors and other service providers to diagnose ASD.** This means that the information in this report reflects the ASD criteria in the previous edition, DSM-IV-TR.

Current ADDM Network Sites, Tracking Years 2014–2016

Legend:
- Monitoring 8-year-olds
- Monitoring 4- and 8-year-olds
- Autism, Cerebral Palsy
- Autism, Intellectual Disability
- Autism, Cerebral Palsy, Hearing Loss, Intellectual Disability, and Vision Impairment

The exact impact that *DSM-5* will have on estimates of the number of children identified with ASD is unknown. An initial analysis using information from the ADDM Network found that estimates of the number of children identified with ASD might be lower using the current *DSM-5* criteria than using the previous *DSM-IV-TR* criteria (35). As doctors and other service providers start using the *DSM-5* criteria, they might diagnose ASD using new or revised tools or they might document symptoms differently. These changes in everyday community practice could alter the *DSM-5*'s effect on estimates of the number of children with ASD. Because of the way that it collects information, the ADDM Network is uniquely positioned to track these changes. The ADDM Network will be able to use both the previous *DSM-IV-TR* and the current *DSM-5* criteria to estimate the number of children with identified ASD from tracking year 2014 and onward. CDC will continue to evaluate the effect of using the *DSM-5* on trends in how doctors diagnose ASD. CDC will also continue to examine how other service providers, such as educators, evaluate and document symptoms as they transition to using the *DSM-5* criteria.

What else is the ADDM Network doing?

Ongoing tracking is essential to our understanding of ASD. Since 2000, the ADDM Network has continued to collect and analyze information to produce estimates every two years of the number and characteristics of children with ASD among 8-year-old children. In 2010 and 2012, the Early ADDM Network, a subset of the ADDM Network, tracked ASD among 4-year-olds in areas of Arizona, Missouri, New Jersey, Utah, and Wisconsin. Beginning with the 2014 tracking year, the Early ADDM Network tracked ASD among 4-year-olds in areas of Arizona, Colorado, Missouri, New Jersey, North Carolina, and Wisconsin. Some ADDM Network sites also track the number and characteristics of children with other developmental disabilities including cerebral palsy, intellectual disability, hearing loss, and vision impairment.

The ADDM Network continues to analyze ADDM Network findings to answer questions about potential risk factors for ASD and characteristics of children with ASD, and to understand more about changes in ASD over time. In 2011, CDC brought together a diverse group of professionals and community stakeholders to develop a plan to better understand changes in ASD prevalence over time. The summary of the "Workshop on U.S. Data to Evaluate Changes in the Prevalence of Autism Spectrum Disorders" is a valuable resource that can help researchers and others better understand the changes in the number and characteristics of children with ASD. A full list of publications and reports based on CDC's work in ASD can be found on our website at www.cdc.gov/autism.